

# Characteristics of referrals to an inpatient hospice and a survey of general practitioner perceptions of palliative care

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## SUMMARY

In order to determine symptoms, drug prescribing and physical problems of patients referred to an inpatient hospice, case notes from 130 consecutive first admissions (95 general practitioner (GP) referrals, 35 consultant referrals) were analysed. GP referrals were more likely to be constipated, require care and be discharged to home. Consultant referrals were more gravely ill, dependent and more likely to die in the hospice. On admission 76 (58%) patients were receiving opiates with co-prescription of opiate and laxative occurring in 41% (31/76) of the cases. The prescription of laxatives with the symptoms of constipation occurred in 62% (26/42) of the cases on admission. A telephone survey of 79 referring GPs revealed that 37% had attended neither a course nor a lecture relevant to palliative care in the past 3 years. GPs experienced difficulties frequently or always in: (a) managing pain (8/79); (b) managing other symptoms (25/79); (c) helping patients and relatives cope with their emotional distress (18/79); and (d) coping with their own emotional responses to death and dying (5/79).

In conclusion, the differences demonstrated between the GP and consultant referrals have implications for purchasers. The high incidence of possible opiate-induced side-effects and the difficulties with symptom control expressed by some GPs indicate a continuing need for effective educational input.

## INTRODUCTION

The rapid growth of specialist domiciliary and inpatient hospice services<sup>1</sup> has resulted in another referral interface between primary and secondary care and also between secondary care services. The advent of fund holding in general practice and NHS (National Health Service) Trust formation has led to close examination of the nature of referrals and to the requirement for workload and clinical data to aid the placing of contracts with providers. A study was designed to examine the symptoms, drug prescribing and management problems of first referrals to a hospice from GPs and hospital consultants. This was followed up by a telephone survey of referring GPs' educational experience and perceived problems with practising palliative care in order to compare changes that may have occurred since the survey conducted by Haines and Booroff in 1986<sup>2</sup>.

The setting was the Exeter and District Hospice opened in August 1992, a 12-bed inpatient unit situated in the grounds of the District General Hospital (854 beds) serving Exeter. The hospice has an outpatient facility, day care

centre and domiciliary hospice service serving Exeter and most of East Devon (health district population 310 000). The hospice's medical director is employed as Consultant in Palliative Medicine to the adjacent Hospital Trust and has support in the hospice from two part-time clinical assistants. Referrals from other hospital consultants are assessed on the wards by the hospice medical director. Referrals from general practice are either by telephone to a hospice doctor or to the hospice homecare team by a referral form.

## METHODS

The study was conducted from 1 June–31 December 1993 and included all first-time referrals, excluding admissions from day care procedures and re-admissions. After the admission was completed the medical and nursing notes were reviewed in a standardized fashion using as comprehensive a checklist as possible. The areas assessed on admission were demographic factors, pre-admission treatments, symptoms (as judged from the admitting clinicians' notes), management problems (including indwelling catheters and presence of a subcutaneous infusion pump), social problems and mobility score (using the scale of fully independent, mobile with help and bedbound). The notes were re-examined between 48–72 h, 96–120 h after admission and at death, for any interventions that may have occurred (from a list of catheterization, subcutaneous

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infusion pump started, nerve block, radiotherapy, transfusion, intravenous infusion, paracentesis or pleural tap and any other significant intervention), referrals to other professionals and mobility score.

From the admission notes the regular medication on admission was recorded in accordance with the *British National Formulary* classifications. The total dose of opiate was calculated in milligram equivalents of morphine using multiplication of the diamorphine dosage by three. Dosage amounts of opioid drugs and compound analgesics were not included in the total dose of opiate received. Whether or not opiate was administered by subcutaneous pump infusion was noted. Co-prescription of opiates with laxatives and antiemetics was recorded as was route of administration of opiates. Chemotherapy included hormonal preparations such as tamoxifen and cyproterone acetate. Patients' drug charts were reassessed at 48–72 h, 96–120 h after admission and at death.

Following the end of the admission the patient's GP was telephoned and asked to participate in a standardized interview requesting details of previous palliative care educational experience over the past 3 years. Using the responses of never, occasionally, frequently, or always, GPs were asked to state if they had problems with the following situations in palliative care: (a) controlling pain; (b) controlling other symptoms (and being asked if any one symptom caused particular problems); (c) coping with patients' and relatives' emotional distress associated with dying; and (d) coping with their own emotional responses to death and dying. Comments regarding their own attitudes to palliative care were invited. GPs were only interviewed once after their first referral.

The results were entered on to computer and analysed with comparisons between GP and consultant cases being made. Tests of statistical significance were performed where appropriate.

## RESULTS

There were 130 referrals (95 from GPs and 35 from consultants) and at 48–72 h 120 patients (88 GP, 32 consultant) and at 96–120 h 100 patients (75 GP, 25 consultant) were present for reassessment. Of GP referrals 43 (45%) died, 42 (38%) were discharged home and 10 (11%) discharged elsewhere, and of consultant referrals 27 (77%) died, seven (20%) were discharged home and one (3%) discharged elsewhere. ( $\chi^2=18.6$   $P<0.03$  comparing the two referral groups). Fourteen referrals (11%) died within 24 h of admission.

Cancer diagnoses were: lung 22 cases (17%); colon 14 (11%); breast 10 (8%); prostate 10 (8%); carcinomatosis alone 9 (7%); pancreas 8 (6%); and bladder 8 (6%). The median time since diagnosis was 12 months for GP referrals

and 5 months for consultant referrals. There was access to the domiciliary hospice service in 125 (96%) of cases and the service was involved in 84/125 (67%) of referrals. Median length of admission was between 6 and 7 days (range 1–45 days).

Significant symptoms on admission were recorded with the following frequencies: pain 79 (61%); constipation 42 (32%) [GP 36(38%) versus consultant 6 (17%)  $P=0.025$ ]; nausea 39 (30%); vomiting 34 (26%) [nausea and vomiting 54(42%)]; anorexia 22 (17%); confusion/agitation 22 (17%); dyspnoea 21 (16%); weakness 9 (7%); insomnia 8 (6%); depression 8 (6%); and fear/anxiety 8 (6%). There were no significant differences between the two referral groups other than indicated. Other symptoms also listed with an incidence less than 5% were: diarrhoea; cough; haemoptysis; oedema; and anaemia.

Social and management problems are shown in Table 1 with significantly more of the referrals by consultants having a urinary catheter or subcutaneous infusion pump *in situ* and a requirement for terminal nursing care. GP referrals were significantly more likely to have a requirement for respite care.

Mobility scores on admission and at each reassessment showed consultant referrals to be significantly less mobile than GP referrals (Table 2).

The interventions and referrals at 48–72 h ( $n=120$ ) were: catheterization 6 (5%); subcutaneous infusion pump started 16 (13%); nerve block performed 5 (4%); transfusion 2 (2%); intravenous infusion 3 (3%); paracentesis 3 (3%); and referral to another consultant 6 (5%).

At 96–120 h ( $n=100$ ) the following new interventions had been recorded: catheterization 4 (4%); subcutaneous infusion pump started 17 (17%); nerve block performed 2

Table 1 Social and physical problems on admission

Social/physical problem*	Total (%) [n=130]	GP (%) [n=95]	Consultant (%) [n=35]
Relatives needing respite care	31 (24)	30 (32)	1 (3)†
Patient living alone	12 (9)	10 (11)	2 (6)
Urinary catheter <i>in situ</i>	19 (15)	8 (8)	11 (31)†
Subcutaneous infusion pump <i>in situ</i>	25 (20)	9 (10)	16 (46)†
Urinary incontinence	7 (5)	5 (5)	2 (6)
Pressure sores	13 (10)	10 (11)	3 (9)
Malignant effusion/ascites	4 (3)	3 (3)	1 (3)
Requirement for terminal nursing care	32 (25)	15 (16)	17 (49)†

\*Also listed with total incidences less than 3% were: hypercalcaemia; faecal incontinence; lack of night/weekend support; inadequate home conditions.

†Statistically significant difference between GP and consultant groups ( $P<0.01$ )  
GP=General practitioner; Consult=consultant

Table 2 Mobility scores derived from medical and nursing notes

	Admission*		k-48-72 h*		k-96-120 h*	
	GP(%)	Conslt(%)	GP(%)	Conslt(%)	GP(%)	Conslt(%)
	[n=88]	[n=33]	[n=88]	[n=32]	[n=75]	[n=25]
Independent	30 (34)	3 (9)	25 (28)	1 (3)	21 (28)	0 (0)
With help	35 (40)	15 (46)	33 (38)	12 (38)	21 (28)	6 (24)
Bedbound	23 (26)	15 (45)	30 (34)	19 (59)	33 (44)	19 (76)

\*Mobility scores at admission, 48-72 h and 96-120 h after admission show a statistically significant difference between the GP and consultant groups.  
GP=General practitioner; Conslt=consultant

(2%); referral to another consultant 5 (5%); and to a social worker 1 (1%).

Table 3 illustrates analgesic prescribing on admission. Significantly more patients were receiving slow release morphine tablets from GPs compared with consultant referrals, though significantly more consultant referrals were receiving opiate via subcutaneous pump infusion on admission.

Table 4 illustrates opiate dosage on admission and at death or discharge. Significantly more consultant referrals were receiving opiate on admission when compared with GP referrals ( $\chi^2=53.2$ ,  $P<0.01$ ). Although the mean opiate dosage on admission of GP referrals was higher than consultant referrals there was no significant difference in median dosages (avoiding distortion of a few very high dosages). Median opiate dosage at discharge was half that at death. Co-prescription of laxative and antiemetic with opiate and prescription of laxative with the symptom of constipation and of antiemetic with the symptoms of nausea and/or vomiting are shown in Table 5. On admission co-prescription of laxative with opiate was observed in only 41% of cases and of antiemetic with opiate in 64% of cases. Only 62% of referrals with the symptom of constipation were receiving a laxative whilst 80% of those with nausea and/or vomiting received an antiemetic.

Frequency of drugs prescribed for the 130 referrals were as follows: antiemetics 65 [50% with 9/65 (14%) receiving two antiemetic drugs]; corticosteroids 35 (27%); tranquilizers 20 (15%); hypnotics 17 (13%); antidepressants 15 (11%); chemotherapy 14 (11%); and anticonvulsants 10 (8%). Laxatives were prescribed for 52 (40%) [GP 42 (44%) versus consultant 10 (29%)] of referrals. During admission the tranquillizer midazolam was used in the control of agitation and terminal restlessness in 33 patients [(all of whom died), 33/70 (47%) of patients dying in the hospice].

Telephone interviews were conducted with 79 GPs (one declined to participate). Over the previous 3 years: 26 (33%) had attended a lecture relevant to palliative care; 24 (30%) a course (lasting 1 day or more) relevant to palliative care; and 29 (37%) neither. Table 6 illustrates the responses

Table 3 Analgesic prescribing on admission

	Total (%)	GP (%)	Conslt (%)
	[n=130]	[n=95]	[n=35]
Slow release morphine tablets	42 (32)	36 (38)	6 (17)*
Morphine elixir or tablets	14 (11)	14 (15)	0 (0)*
Opiate via subcutaneous infusion	25 (19)	8 (8)	17 (49)**
Compound analgesics	26 (20)	21 (22)	5 (14)
Paracetamol	13 (10)	12 (13)	1 (3)
Non-steroidal anti-inflammatory drugs	29 (22)	24 (25)	5 (14)

\* $P<0.05$ , \*\* $P<0.01$ : statistically significant difference between GP=General practitioner; Conslt=consultant

Table 4 Opiate prescribing and dosages at admission, death and discharge

	Total (%)	Death total (%)	Discharge total (%)
	[n=130]	[n=70]	[n=60]
Receiving opiate	76 (58)	63 (90)	32 (53)
Mean dose (mg)	182	224	251
Median dose (mg)	75	120	60
Dose range (mg)	20-1600	20-1140	20-1600

to the questions concerning GPs' perceptions of problems with various aspects of palliative care compared with two similar studies' results<sup>2,3</sup>. Controlling pain presented problems frequently for 8% of respondents, whilst 25% had problems, frequently or always, in controlling other symptoms apart from pain (with nausea, vomiting and dyspnoea being listed most frequently).

Helping patients and relatives cope with their emotional distress was frequently a problem for 18% of respondents, but coping with their own emotional responses to death and dying were cited as a problem (frequently or always) by only 5% of respondents. Accompanying comments included:

**Table 5 Prescriptions of laxative with opiate and with symptom of constipation and prescription of antiemetic with opiate and with symptoms of nausea and/or vomiting**

	Admission (%)			Death total (%)	Discharge total (%)
	Total	GP	Consult		
Co-prescription					
Opiate and laxative*	31/76 (41)	25/51 (49)	6/25 (24)	32/63 (51)	26/32 (81)
Opiate and antiemetic	49/76 (64)	31/51 (61)	18/25 (72)	50/63 (79)	23/32 (72)
Prescription					
Laxative with symptom of constipation	26/42 (62)	21/36 (58)	5/6 (83)	N/A	N/A
Antiemetic with symptoms of nausea and/or vomiting	43/54 (80)	29/39 (74)	14/15 (93)	N/A	N/A

\*Statistically significant difference between GP and consultant referrals on admission ( $P<0.01$ )

GP=General practitioner, consult=consultant; N/A=not applicable

**Table 6 Problems experienced by general practitioners (GPs) in caring for terminal ill patients—this study compared with Haines and Booroff (1986) and Wakefield *et al.* (1993)**

Problems	Number of respondents (percentage) replying			
	Never	Occasionally/sometimes	Frequently	Always
Controlling pain				
This study	8 (10)	65 (82)	6 (8)	0
Haines & Booroff (Ref 2)	13 (7)	119 (61)	59 (30)	4 (2)
Controlling other symptoms				
This study	2 (3)	57 (72)	19 (24)	1 (1)*
Haines & Booroff (Ref 2)	6 (3)	108 (55)	79 (40)	3 (1)
Wakefield <i>et al.</i> (Ref 3)	7 (7)	65 (61)	32 (30)	2 (2)
Coping/dealing with emotional distress of patients and relatives				
This study	22 (28)	43 (54)	14 (18)	0
Haines & Booroff (Ref 2)	12 (6)	96 (49)	73 (37)	14 (7)
Wakefield <i>et al.</i> (Ref 3)	5 (5)	38 (36)	44 (42)	18 (17)
Coping with your own emotional responses to death and dying				
This study	20 (26)	54 (69)	3 (4)	1 (1)
Haines & Booroff (Ref 2)	69 (36)	85 (44)	33 (17)	7 (4)
Wakefield <i>et al.</i> (Ref 3)	32 (31)	60 (59)	6 (6)	4 (4)

\*Symptoms stated as causing particular problems were: vomiting 13; nausea 11; dyspnoea 9; and psychological 5.

I have become hardened (to death and dying) over the years—which is a pity... three young people in succession dying got to me... dying is a crucial part of life and if handled well is beneficial for the carers... I am always upset by the death of a patient... it is one of the reasons why I wish to leave medicine.

## DISCUSSION

The future role of hospices in the new purchaser-provider environment of the NHS has been recently discussed with emphasis on purchasing authorities to take a more active role in assessments of palliative care need<sup>4</sup>. The study reported in

this paper has revealed a number of significant differences between hospital-based consultant referrals and community-based GP referrals. Consultant referrals had been diagnosed for a shorter period before admission, had a higher requirement for terminal nursing care and patients were more likely to die during the admission when compared with GP referrals. Consultant referrals were also more likely to have a subcutaneous infusion pump and urinary catheter *in situ* and be significantly less mobile on admission and throughout the whole admission. Conversely, GP referrals were more likely to require respite care and to be discharged to home. These results show that patients referred by

consultants are more gravely ill, dependent and in a terminal phase of illness compared with GP referrals. The requirement by consultant referrals for terminal care and by GP referrals for respite care is a trend observed in a previously reported pilot study of 12 hospice services<sup>5</sup>. Wilkes in 1984<sup>6</sup> commented that in his study the difficulties of relatives were more often a cause for hospital admission than those of the patients. This observation is borne out, in part, in this study where the need for respite care, terminal nursing care, and the presence of conditions requiring nursing care (such as pressure sores, urinary incontinence), were cited as reasons for referral. Determining the factors leading to referral for respite care and terminal nursing care was not always possible from the notes or referral letters. However, lack of provision of adequate home nursing care leading to referral has been a factor often described in previous studies<sup>2,7,8</sup>. In the study area there was universal coverage for domiciliary hospice nursing advice, but minimal provision of 24 h home nursing care, that would enable a patient living alone to be nursed at home or provide adequate respite for relatives. A recent study in the same health district<sup>9</sup> indicated that inpatient management of terminally ill patients would have been altered in one in six cases had 24 h home nursing care been available, suggesting that such services could alter referral patterns.

The symptoms and medical problems on admission were in accord with previous studies with pain being a feature in 60% of cases and no significant difference between the two referral groups<sup>5,10-12</sup>.

Despite the fact that pain rating scales were not used in the medical and nursing notes the high level of reported pain is disappointing, especially considering the widespread involvement of the domiciliary hospice service. This is discussed below in connection with the perceived ability of GPs to control pain.

The most common intervention during admission was the employment of a subcutaneous infusion pump for the administration of opiates, antiemetics and tranquillizers. This intervention was associated with a final outcome of death and reflected the decreasing ability of the patient to take oral medication.

Although this study did not confine itself solely to patients dying in a hospice, as compared with the study of Rees<sup>13</sup>, it is possible to draw some useful conclusions concerning prescribing for symptoms of pain, constipation, nausea and vomiting.

In accordance with good prescribing guidelines no patients on admission were being prescribed analgesic cocktails (such as Brompton's mixture). The majority of GP referrals receiving opiates were receiving them in the form of oral morphine slow release tablets, a formulation which has been promoted in World Health Organization (WHO) guidelines<sup>14</sup>. The median daily dose of opiate was

similar for both GP and consultant referrals despite differences in the routes of administration (consultant referrals receiving opiate via the subcutaneous infusion route in significantly more cases). The median daily dose on discharge of patients was, in fact, lower than on admission whilst the median dose for patients dying in the hospice had risen from 75 mg to 120 mg. The lower dose on discharge probably reflects hospice usage of non-opioid analgesics and co-analgesics and the attention paid in the hospice to the numerous other factors that influence pain perception, e.g. alleviation of fear and anxiety, attention to other distressing symptoms.

The co-prescription of laxatives with opiate drugs was around 50% (GP referrals), somewhat lower than in a GP study in Scotland where co-prescription rates of 58-64% were reported<sup>15</sup>. For patients being discharged on opiate co-prescription of laxative had risen to 80% and would be in accordance with good practice guidelines<sup>16</sup>. Co-prescription of laxatives and opiate drugs was particularly low in the consultant group (24%) and compared unfavourably with figures of 76-78% quoted in a study from a specialist cancer hospital<sup>17</sup>.

The symptom of constipation was mentioned in 42 of 130 cases on admission and the prescription of laxative occurred in 62% of this group. Guidelines would indicate that where opiate drugs are prescribed a laxative should usually be provided<sup>16</sup> and there would appear to be room for improvement in this area.

The co-prescription of antiemetic drugs with opiate drugs was encouragingly high (64%) and compared favourably with studies in a specialist cancer hospital (73-74%)<sup>17</sup> and in the community (32-57%)<sup>15</sup>. Patients with symptoms of nausea and vomiting were receiving antiemetic drugs in 80% of cases which is encouragingly high though clearly control of symptoms was not being fully achieved.

The use of the benzodiazepine tranquillizer midazolam (via subcutaneous infusion) in the hospice was widespread with 47% of those dying receiving the drug to alleviate symptoms of agitation and terminal restlessness. This particular drug is not often deployed in the community setting (Seamark D, personal observation) and further education and instruction of GPs in its safe use would be of benefit in the management of those patients in the terminal phase of their illness.

It was encouraging that nearly two-thirds of the GPs referring patients had some palliative care education over the past 3 years and there was positive verbal support for the educational initiatives of the hospice team and local academic GP institute. However, the telephone interview revealed areas where a substantial minority of GPs still experience difficulty. Controlling symptoms apart from pain presented problems always or frequently in a quarter of responses in line with responses of 41% from the study of Haines and

Booroff<sup>2</sup> and 32% from the Australian study of Wakefield and colleagues<sup>3</sup>. Pain control was reported as a frequent problem in only 8% of responses which is far less than the 24% in the Haines and Booroff study, which might indicate on a more confident approach to pain control over the time between these studies. This is supported by the findings of a Scottish GP study which found that 80% of GPs were prepared to manage malignant pain on their own<sup>5</sup>. The dichotomy between reported pain and GPs' perceived ability to deal with pain may be partly explained by: the stoicism of patients not wishing to complain to their family doctor; pain associated with transfer to the hospice and with the impact of a new environment; and the fact that referrals for inpatient care can represent a group of patients with difficult problems of symptom control (borne out by the fact that only 35% of the total referrals to the hospice service receive inpatient care).

The emotional distress of patients and carers consistently appears to cause GPs more problems than dealing with their own emotions as borne out by the other two quoted studies. How much of this apparent resilience is due to training and experience is hard to ascertain but the personal comments quoted from this study should serve to remind all health care professionals of their vulnerability when dealing with the emotive issues of death and dying. The areas of uncertainty of consultants and educational need in relation to terminal care was not determined owing to the small number involved in the study, but is an area warranting further research.

In conclusion, the differences demonstrated between GP and consultant referrals have implications for purchasing authorities who need to consider that most consultant referrals will die in the hospice and will require terminal nursing care. The high incidence of possible opiate induced side-effects (constipation, nausea and vomiting) and the substantial minority of GPs experiencing difficulties with symptom control have implications for Family Health Services Authorities in terms of educational support for GPs and community support services. Despite recent educational experience a substantial minority of GPs still experience difficulties with symptom control and with emotional issues surrounding death. With the increasing interaction between GPs and hospice staff there are opportunities for educational input and emotional support which could address these areas.

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